“Perceived Vulnerability and its impact on the experiences of people with intellectual disabilities”

Background

Stigma is instigated through society’s judgement on what it deems undesirable, causing the devaluation of a person’s identity. People with intellectual disabilities are classed as socially different therefore undermining their identity as a ‘normal’ member of society.

Objectives

The principal research is based on how people with disabilities navigate stigma to form lasting relationships. The aim of this study is to explore how people with intellectual disabilities navigate stigma in their daily lives and their experiences of being treated differently.

Methods

A qualitative research method was chosen, using critical disability theory as a guiding concept. It proposes that disability is a social construct of our society. The experiences of seven people with intellectual disabilities aged from 20 to 53 were explored. Thematic analysis was completed and ATLAS.ti was used for data analysis.

Results

The participants had varying levels of understanding regarding their disability, none of them had a complete awareness of what disability meant and the implications that it has in their lives. The participants were involved in a variety of activities but the commonality was the overwhelming level of support, supervision and control being provided at all times.

Conclusions

People with intellectual disabilities are being sheltered from information that would give them a full awareness of their own disability. Families and the services involved in their care are creating a protective capsule around them from the stigmatisation associated with disability. This protection is necessary at times, but the perceived vulnerability of people with intellectual disabilities is hindering their autonomy and expression of individuality.
Introduction

Disability occurs when society and the environment impose restrictions on people with impairments (Fulcher and Scott, 2007). This results in prejudice or acceptance of questionable societal norms, leading to the stigmatisation of the person due to their divergence from these so-called norms (Jahoda and Markova, 2004). Stigma causes the devaluation of a person’s identity. Edgerton (1967) discussed that an awareness of stigma derives a struggle to defeat a spoiled identity and the need to pass as normal. It is the social reaction that centres on a specific attribute that is used to diminish a person’s identity and individuality (Fulcher and Scott, 2007). In this study the aim is to explore how people with intellectual disabilities navigate stigma in their daily lives and their experiences of being treated differently.

Literature Review

Our assumption of another’s social identity leads to the construct of stigma. Society’s judgement on specific traits is central to what it deems undesirable. It is our culture exercising its own discrimination which without specifically intending to reduce a person’s sense of self-worth (Goffman, 1963). Stigma embodies a label and a stereotype that links a person with a set of what we pertain to be undesirable characteristics and this forms a stereotype (Link and Phelan, 2001). Attitudes can be both positive and negative however stigma is explicitly comprised of negative attitudes. Stereotypes are attitudes concerning a substantial group of people which enable us to produce ideas and expectations of entire social groups (Hamilton and Sherman 1996). Terms that have been previously politically correct regarding disabilities rapidly alter to pertain a term of abuse due to the stigma attached to the identity (Beart et al. 2005).

Our prejudicial culture leads us to make assumptions regarding a person’s identity. Our social identity categorises us according to our attributes, be it physical, mental or cultural characteristics (Goffman 1963). Each social category is associated with particular features and traits, acceptance of our own social category does not inevitably indicate acceptance of those associated characteristics (Ashforth and Mael, 1989). People with intellectual disabilities experience stigma as it is classed as a social difference which undermines the
identity of the person as a ‘normal’ member of society (Fulcher and Scott, 2007). People with intellectual disabilities are one of the most stigmatised groups in our society (Ali et al. 2012).

Educating our society with regards to intellectual disabilities would allow for informed decisions to be made regarding perceived stereotypes (Corrigan and Watson 2002). The Disability Act 2005 defines “disability, in relation to a person, as a substantial restriction in the capacity of the person ……… by reason of an enduring physical, sensory, mental health or intellectual impairment” (The Disability Act, 2005). Intellectual disability is defined as a ‘significantly below-average level of intellectual functioning with associated impairments in adaptive functioning, arising before the age of 18 years’ (APA, 2000). This label will remain forever attached to the person’s identity and being; and as a result it is something that can never be lost. Intellectual Disability as a term has evolved from a previously restrictive and unconstructive term of mental retardation to something more focused on the capabilities of that person within the constraints of their own environment (Atchison and Dirette, 2012).

Many people with intellectual disabilities experience the stigma of their social identity through their interactions with others (Beart et al 2005). It is felt that the inclusion of people with intellectual disabilities would reduce the misconceptions about their abilities. Enabling inclusion would challenge people’s preconceived perceptions of the characteristics of an intellectual disability (Morin et al. 2013). Emphasising the capabilities of people with intellectual disabilities would lead to an improvement in attitudes (Scior, 2011). However according to Beart et al. (2005) many health professionals working with people with intellectual disabilities don’t acknowledge or recognise the alternative identities that are crucial to a person’s sense of self and individuality. The intellectual disability becomes a person’s principal identity (Beart et al. 2005). A stigmatised person with an intellectual disability is now defined by his so called deviance (Macionis and Plummer, 2005).

People with intellectual disabilities may have problems understanding the terms that are used to categorize them (Beart et al. 2005). The U.N. Convention of the Rights of People with Disabilities (UNCRPD) was established to foster, guide and safeguard the inherent rights of people with disabilities. The core purpose of the UNCRPD is to validate and exemplify people with disabilities intrinsic right to freedom and dignity in all aspects of their lives (UNCRPD, 2006). The UNCRPD has not yet been ratified in Ireland. The Irish Government is liaising with The National Disability Authority to identify the actions required to ensure Ireland will be in compliance to ratify by 2016 (Department of Justice and Equality, 2012).
Ireland has seen a major shift in the provision of community services for people with intellectual disabilities (Kilcommons et al. 2012). In Ireland, half of all people with an intellectual disability now live with a family carer (McConkey et al. 2006). This change from institutionalised care was forged by Wolfensberger. Wolfensberger defined Normalization as “utilization of means, which are as culturally normative as possible in order to maintain and / or establish personal behaviour, and characteristics, which are as culturally normative as possible” (Wolfensberger 1972). Irish People with intellectual disabilities are restricted in their legal capacity due to the perceived perception that they are unable to make their own decisions or know their own mind (Doyle and Flynn, 2013). This is central to the perceived ideation of the need to protect the vulnerable in our society without giving them the opportunity to make support decisions.

The World Report on Disability recommends that people with disabilities are involved with the development of policies as they have a unique insight into their own disability and should be actively involved through to service delivery. People with disabilities are entitled to control their own lives and should be consulted regarding issues which relate directly to them (World Health Organisation, 2011). The concept of involving people with intellectual disabilities through consultation has been limited in relation to intellectual disabilities and stigma in previous literature, due to the implications of the perceived lack of ability (Doyle and Flynn, 2013). The aim of this study is to gain an insight into the experiences of people with intellectual disabilities in relation in how they navigate stigma and their insight into being treated differently.

Methodology

In this qualitative research, the researcher delved into how people with intellectual disabilities describe and comprehend their lives through an exploration of their perspectives and everyday realities by observing, documenting, analysing and interpreting (Grbich, 1999; Hammell et al. 2000). Qualitative Research was chosen for this project as it is based on the principle that people are intrinsically linked to their contexts and environments (Hammell et al. 2000). This is crucial to explore how people with intellectual disabilities understand their disability and the implication in their daily lives. Critical Disability Theory was chosen as the guiding concept for this research as it centres on the perspective of people with disabilities.
and incorporates the fact that disability is a social construct of our own society (Hosking, 2008). It enables people with disabilities to challenge the preconceived attitudes and beliefs imposed by society (Pothier and Devlin, 2006).

Data Collection

The participants were recruited using purposive and convenience sampling and were approached and selected for inclusion if they met the criteria. The criteria used were someone with an intellectual disability aged between 18 and 55 who attended a service in the locality. This maximised convenience and minimised the cost (Esterberg 2001; Grbich, 1999; Bryman, 2001). The participants were recruited through information sessions which were held in services for people with intellectual disabilities. An information letter and research poster was provided at the session and any questions or queries were addressed and resolved. This ensured the participants were informed and understood the concept of the interview process thus allowing for a more in-depth interview (Grbich, 1999).

Seven participants were interviewed for this study. There were three male and four female participants aged from 20 to 53. Five of the participants live at home with their families and two of the participants live in shared community housing for people with intellectual disabilities. All of the participants were involved in a service Monday to Friday. The participants had the option of having a key worker sit in on the interview and two participants took up this option. Prior to the commencement of each interview, an accessible information sheet and consent form with pictures supporting each statement was talked through. It was signed by all to ensure the nature of the research was understood and what would happen to the information. This research is a part of a wider project lead by a principal researcher and therefore the data collected will be amalgamated with other projects to create a database of collated information.

Ethical Considerations

The interviewer conducted seven in-depth semi-structure interviews over a one month period using an accessible interview guide set forth by the principal research. A semi-structured interview process was chosen as it allowed the interviewer to guide the interview using non-directive questions that were relatively open ended (Bryman, 2001; Hammell et al. 2000). The interviewer allowed the interviewees the opportunity to develop and provide a detailed and comprehensive response (Bryman, 200; Hammell et al. 2000). The interviewer aimed to
discover the participant’s experiences and feelings by allowing them the opportunity to express their own opinions and ideas surrounding how they navigated stigma and their experiences of being different (Esterberg 2001).

The data was recorded, transcribed and analysed using thematic analysis as described by Braun and Clarke. It allows for the organisation and description of the data set in great detail and enables the researcher to interpret various aspects of the research. The initial stage was becoming familiar with the data through the transcribing and subsequent reading. The second stage involved generating initial codes (Braun and Clarke, 2006). The interviews were coded through Atlas.ti. These developed codes were used to frame the remaining data. The coding process allowed for the data to develop itself without being forced into predestined structures (Flick, 2004). The third and fourth stage for this study was gathering the initial codes into potential themes. This was done by weaving together the emerging themes and key ideas from the transcripts to form the preliminary findings (Hammell et al. 2000; Braun and Clarke 2006).

Ethics for this project was obtained through The University of Limerick Education and Health Science Research Ethics Committee, Health Service Executive and Daughters of Charity. All participants are provided with an introductory letter which disclosed the clear purpose and requirements of the study (Jenkins et al. 1998). All participants gave informed written consent using the consent form with embedded pictures. The researcher continually reiterated that the study was voluntary and that they could conclude the process at any time. The principal investigator and the research student alone will have access to the transcripts. Pseudonyms will be allocated to all participants and will be maintained through to any publication or presentation to ensure the protection of their anonymity.

Trustworthiness

Trustworthiness was ensured through meeting Guba’s (1981) criteria. A full description of the research process was provided to enable transparency and transferability (Curtin and Fossey, 2007). Through the process the participants were encouraged to seek clarification and query the process if needed (Shenton, 2004). To ensure that the information was represented truly without bias, the researcher utilised the support of their peers to debrief and explore the emerging themes. The researcher had to acknowledge the need for reflexivity as they were also a contributor to the process; by recognising personal biases, assumptions and values that they held (Finlay, 2003). The procedure of keeping a reflective journal and completing field
notes after each interview allowed for the separation of the participant’s perspective from that of the interviewer’s to ensure the findings were unbiased (Curtin and Fossey, 2007).

Findings

Each participant discussed at length their weekly routine, with whom they spent their time and who they were comfortable with. The participants varied in their understanding of disability and in their experiences of being different. All the participants displayed some awareness of disability and the implications it caused. In this study the findings relating to the participants understanding of disability and their perceived vulnerability were explored.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Housing</th>
<th>Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greg*</td>
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<td>Service Provider 1</td>
</tr>
<tr>
<td>Valerie*</td>
<td>Female</td>
<td>39</td>
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<td>Eimear*</td>
<td>Female</td>
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<td>Service Provider 1</td>
</tr>
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<td>Michelle*</td>
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<td>Family Home</td>
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<td>Justin*</td>
<td>Male</td>
<td>22</td>
<td>Family Home</td>
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</tr>
<tr>
<td>James*</td>
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<td>Family Home</td>
<td>Service Provider 2</td>
</tr>
<tr>
<td>Kate*</td>
<td>Female</td>
<td>20</td>
<td>Family Home</td>
<td>Service Provider 2</td>
</tr>
</tbody>
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*Names provided to the participants to ensure anonymity

The guide that was used during the interviews was constructed on the participant’s awareness of their own disability. During some of the interviews the guide had to be adapted to coincide with the participant’s view of their own disability. When a participant disclosed that didn’t have a disability, the interview guide was altered to stop addressing their disability specifically but their attitude and understanding of the topic. In this case the participants responded by discussing people with disabilities or friends of theirs who had a disability. The interviewer aims to explore the themes of understanding disability, perceived vulnerability and experiencing difference.

Understanding Disability
The level of awareness varied from participant to participant but it was clear that none of the participants involved realised the true concept of what a disability, specifically an intellectual disability, was and the inference it provided. The definitions and explanations varied on the meaning of disability, one participant stating it was “good”, when asked. This brought to mind the possibility that this was a response she had herself been given when enquiring. Another participant suggested that “it means…..that people doesn’t get on …. Fighting”; specifically referring to other people with intellectual disabilities.

The participants understood disability distinctly in the physical realm. Three of the participants associated people with physical disabilities primarily when asked what a disability was; “someone in a wheelchair”, or someone who “couldn’t walk properly and ... had a push thing”. None of the participant’s spoke about intellectual disabilities directly being part of a disability definition. Three participants made reference to people who couldn’t “read or write” or “people who has like special needs”. One participant explaining a “learning disability is you’re not as bright”. One participant referred to his epilepsy and seizures as his disability and something that makes his life more difficult;

“Sometimes I would say yes that would only be if it was close to the end of the week because tiredness starts setting in with seizures”.

Only two of the participants explicitly referred to themselves as having a disability, “people who have the same as me, have a disability”. One participant enquired during the process why it happened to her.

“Why did it happen to me, it didn’t happen to my brother and my sisters are all normal, my nieces and nephews are all normal……they all perfect. Is it my parent’s fault?”

This participant became emotional during the process while discussing the meaning of disability and why she isn’t ‘normal’ like the rest of her family. “I find it hard to accept, I find it hard to cope with……. I wish I didn’t have a disability”. It was evident in the interviews that there was an understanding of disability as the participants skirted around the topic. You would wonder had they ever been given the opportunity to discuss disability and its implications before.

The other participants spoke about people with disabilities without recognising themselves as part of that category. One participant stating that “I know disabilities (people with
disabilities) are different than us” however this participant went on to discuss his involvement with Special Olympics and stated that “people probably think that when you do Special Olympics that you have a disability”. This I felt was significant in displaying this participant’s understanding of disability as he knew he was involved with a service specifically designed for people with disabilities but didn’t recognise that he himself falls into that criterion. “They should be treated the same as us, they should have the same rights; the same as us”.

Perceived Vulnerability

The participants were involved in many activities in the services they were attending. Photography, Art, Drama, Dancing, Cooking, IT., Life Skills, Swimming and going to the gym are only a fraction of the activities that were discussed as part of their routines. Something of interest was the level of support being provided for each activity the participants were involved in. This was also apparent in their home routines. Two of the participants lived in shared community housing run by a service organisation where many of the activities undertaken involved the support of a social care worker. This was also true of the participants living in family homes being that many of the activities were closely supported by family members.

It raised the question as to how much control did the participants have over their own lives. Typically they were involved in a group situation with continuous support. The activities were generally chosen by the participant’s support network and were continually monitored and controlled. The participants were not opposed to this. The impression received by the researcher was of acceptance and normalcy. It appears that participants were guarded from the opportunity to experience being different due to the supervision being provided through support workers and family members. This constant support may have inevitably reduced their experiences of being different and with that stigma. However the participant’s did discuss experiencing difference in reference to being outside the ‘norm’.

Experiencing Difference

Participants discussed their daily routines in depth and what was most evident were the underlying references to feeling different or people looking at you. “I don’t like having a disability cause it upsets me …..I feel different” but they struggled when queried to give any more detail in regarding to what it meant or the significance in their daily lives. Participant’s
experience of difference involved the internal aspects of how it made them feel but also the external aspects of people responses and their reactions. “Sometimes you can see them looking at you”. One participant expands on those differences to include how it makes her feel: “they’re looking at you...It kind of upsets me”. These external aspects were deemed to be some kind of judgement.

The participants who acknowledged having a disability which contributed to feelings of difference referred to themselves as being out of the ordinary. One participant discussed how she feels her level of literacy and visual communication accentuate the differences between her and the people she deems ‘normal’.

“You (speaking about herself) can’t do some of the things people who look normal do. I’m different....I have a disability and they don’t. My eye contact is not great... and sometimes I need help with my spellings”.

The participants who were mindful of their disability discussed wanting to be ‘normal’ and not ‘feel different’ Their understanding of normal was people without disabilities. One may question that if they were granted the opportunity to discuss disabilities would their perception of normal be altered. The participants referred to the aspiration of being like everyone else, “I wish I was normal like yourself and other people”. The perception of being normal really struck me as it came through many of the participant’s responses “I’m not as normal as they are”.

Discussion

Perceived Vulnerability

As a society are we reducing a person’s sense of self and individuality by restricting the information needed for a full understanding to the implications for their life. The restriction of information pertaining to an individual’s disability affects their sense of self determination and autonomy (Cooney et al., 2006). The supporters play an integral part in disclosing information regarding a person’s disability in a manner they see fit. This constructs as Goffman (1968b) states a ‘protective capsule’, to screen and control the experiences and knowledge imparted to people with intellectual disabilities. It is a manner of shielding people from concepts and the preconceived stigma relating to the implications of their disability.
This protective capsule remains a less robust shield into adulthood due to the recognition of the discrepancies between their lives and the lives of their peers (Todd and Shearn, 1997). This protective capsule for the participants involved in this study has yet to be discarded due to the boundaries placed on their independence by their family members and the services they are attending.

It is recognised that there are varying levels of support needed for people with intellectual disabilities. How do you know how much support to provide without restricting the opportunity for supported choice and risk (Finlay et al. 2008). There are valid concerns as evident in the history of people with disabilities regarding abuse and exploitation; however it is crucial to balance the perceived need for protection with a level of autonomy (Seale et al. 2013). Perske (1972) promoted the need for dignity of risk for people with disabilities to be allowed encounter reasonable risk to promote learning. Learning from our experiences is part of life and a major aspect of development. We grow due to the implications of the choices we make. This applies to all beings. As people with intellectual disabilities are often overprotected due to their perceived vulnerability the capacity to learn from their mistakes is removed (Kilcommons et al. 2012).

An article by Johada et al. 1988 states that people with intellectual disabilities don’t associate the identity of having a disability with themselves even if others do. This is reinforced by Todd and Shearn 1997, who affirmed that people with intellectual disabilities have limited knowledge of their disability and its significance in their daily lives. The apparent cause for this lack of insight is felt to be due to the supportive role and the perceived need for the individual’s protection from the toxicity of stigma. This was apparent among all of the participants interviewed for this study. When discussing the activity timetable each and every activity was supervised or chaperoned by a parent or social care worker.

The social care workers and families are a vital aspect to shaping the self-identities of people with intellectual disabilities (Todd and Shearn, 1997). The inadequate knowledge the participants have into their own disability displays this ‘protective capsule’ as an overwhelming debilitating factor into adulthood. None of the participants involved in this research had a clear understanding of what disability meant and therefore the implications this had in their daily life. They are being prevented from an awareness of their own disability through the protective film provided by the supports in their life. They are filtering the information to shelter them from the stigma imparted by society.
Supportive Role

People with intellectual disabilities have decisions regarding their own lives made for them without consultation or involvement due to the perceived need to protect them from the associated stigma (Beart et al. 2005). People with intellectual disabilities who understand their diagnosis find that because family members feel a need to shelter and protect them it inhibits them in making decision about their own lives (Jahoda and Markova, 2004). Due to this implication it means that they are perceived as a vulnerable individual. Support was a continuous theme through the participant’s narratives. There needs to be a review of the supporting role, to enable people make their own choice and guide their decision making rather than a caring role specifically centred on minding (Abbott and McConkey, 2006).

Parents can be reluctant to allow their children, often adults with intellectual disabilities, the opportunity to make choices due to the perceived issue of capacity and consent. People with intellectual disabilities are more likely to find it difficult to identify and assess risk due to their intellectual disability (Kilcommons et al. 2012). Positive risk taking is integral to developing supported decision making for people with intellectual disabilities. It enables people with intellectual disabilities to obtain increased control over their own lives. While incorporating the benefits of independence and wellbeing if successful or the negative risk of potentially failing to achieve the intended goal (Seale et al. 2013).

Due to parent’s innate need to shelter and protect their children with intellectual disabilities, it is often the case that perpetual immaturity is chosen (White and Barnitt, 2000). Many of the activities the participants were involved in were not age-appropriate. Their leisure pursuits were generalised to either the services they were in or the general consensus of the house. The individual was not choosing their own occupational preferences but what suited the group as a whole. Many of the leisure activities and occupations were decided on by the service, social care workers and family members. Staff may not have the training to provide assistance in enabling people to learn and develop new skills, to improve social inclusion, independence and self-efficacy (Abbott and McConkey, 2006). Self-advocacy is shaped by the situation and the nature of the support a person with disabilities receives (Goodley, 2005). For the participants in this study to act autonomously, it is crucial for them to receive support from their families and social care workers involved in their care.

Active support enhances the communication between the person with intellectual disabilities and the social care workers involved. It provides the social care worker the ability to plan
activities with an individual in a structured manner to provide them with opportunities to participate (Jones et al. 1999). Active support increases the participation of a person with an intellectual disability and with that their quality of life as gauged by their engagement in meaningful occupations (Beadle-Brown, 2012). Active support emphasises supported choice making for people with intellectual disabilities. Resulting in a decreased level of support required (Koritsas et al. 2008). I feel that active support would be beneficial to incorporate into how we support people with intellectual disabilities. I feel that it would reduce the perceived vulnerability and promote the ability of supported choice and positive risk taking.

**Limitations to the Research**

The main limitations to this research were that due to time constraints, only one interview per participant was completed. To obtain unassailable results additional interviews per participant would have led to a more rigorous testing of the findings (Hammell et al. 2000). It would have also enabled the interviewer to build a more meaningful rapport with the participants. This in turn may have led to the participants providing additional and more in-depth information as they became more relaxed in the situation (Grbich, 1999). The interviews took place at a location that was familiar to the interviewee to ensure their ease during the process. However due to the lack of control over the location of the interview’s, the researcher had a reduced capacity to guarantee confidentiality. Again as a result of time constraints, Braun and Clarke’s (2006) fifth stage of a thematic analysis was not completed, this study jumped from the fourth to sixth and final stage to produce this paper. To progress with this research and move towards putting it forward for publishing, stage five needs to be revisited and completed(Braun and Clarke, 2006).

**Conclusion and Implications to Practice**

Being client centred is core to what we as occupational therapists model our practice around and it is embedded in our Code of Ethics and Professional Conduct for Therapists (AOTI, 2006). Client centred practice comprises of ‘autonomy/choice, responsibility/partnership, enablement, contextual congruence, accessibility and respect for diversity’ (Duncan, 2012). A therapist can be client centred with clients who are unable to express their autonomy through
designated supporters advocating for said client (AOTI, 2006). People with intellectual
disabilities are sheltered from the stigma associated with their disability and this has resulted
in decisions being made for them due to what their support systems deems best (Beart et al.
2005). People with intellectual disabilities are not being allowed the opportunity to express
their autonomy or show their capabilities (Jahoda and Markova, 2004). As people with
intellectual disabilities are perceived as vulnerable individuals, they are restricted in their
ability to make their own choices (Kilcommons et al. 2012). People with intellectual
disabilities are held back from engaging in positive risk taking (Seale et al. 2013). Our
practice as clinicians is affected because we cannot apply client centred practice with clients
who are able to engage but are being hindered due to the perceived need to protect.

This study set out to explore the level of understanding people with intellectual disabilities
have about their own disability and their experiences of being different. It studied the views
of seven participants’ in relation to their own lives and routines. People with intellectual
disabilities are being withheld the ability to have an awareness of their own disability. Family
members and social care workers strive to protect due to the negative stigma associated with
their disability. It is necessary for supporters to enable people with intellectual disabilities
make supported decisions regarding their own life. This is achieved by affording them the
opportunity to have some independence in their choices while at the same time, offering them
support. It is vital for the families and services to promote positive risk taking as it is a
natural part of our lives and a fundamental aspect to how we learn about ourselves. People
with intellectual disabilities are sheltered and protected by their family members and the
services involved. They are not being granted the opportunity to experience life without a
protective filter and to experience the good and the bad in our society. The experiences we
have shape the people we become so why do we restrict people with intellectual disabilities
from having the opportunity to become the people they want to be. It is acknowledged that
support is necessary at times in varying levels, for different people. However, the perceived
vulnerability is disabling people with intellectual disabilities from achieving their potential.
Reference List


Power, A. (2013) *Understanding the complex negotiations in fulfilling the right to independent living for disabled people*, Disability & Society, 28(2), 204-217.


